



# Risk Communication and Ethical Challenges Associated With Autism Spectrum Disorders

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# Why Autism, Risk Communication & Ethics?

- Very few studies and papers examining Risk communication & ethical issues unique to ASDs
  - None in the context of public health
- Historical controversies demand research in this area
  - These controversies have shaped the behavior of all stakeholders, both present day and historic
  - Debates over autism etiology have raged for more than sixty years
  - Recent debates about autism and vaccination have polarized ASD stakeholders and have had a deleterious impact on the public's health



+ Mothers =

AUTISM



Ingredients: Mercury, Formaldehyde, Aluminum Phosphate, As

WEEKLY

EXCLUSIVE DETAILS  
**Why Jen Took John Back!**  
 Her flip-flop on babies  
 'They can't deny the chemistry'

**BEATING AUTISM**

**HOW I SAVED MY SON**

SHANNA EXCLUSIVE

"When he finally hugged me I prayed, 'Please God don't let this be the only time'"

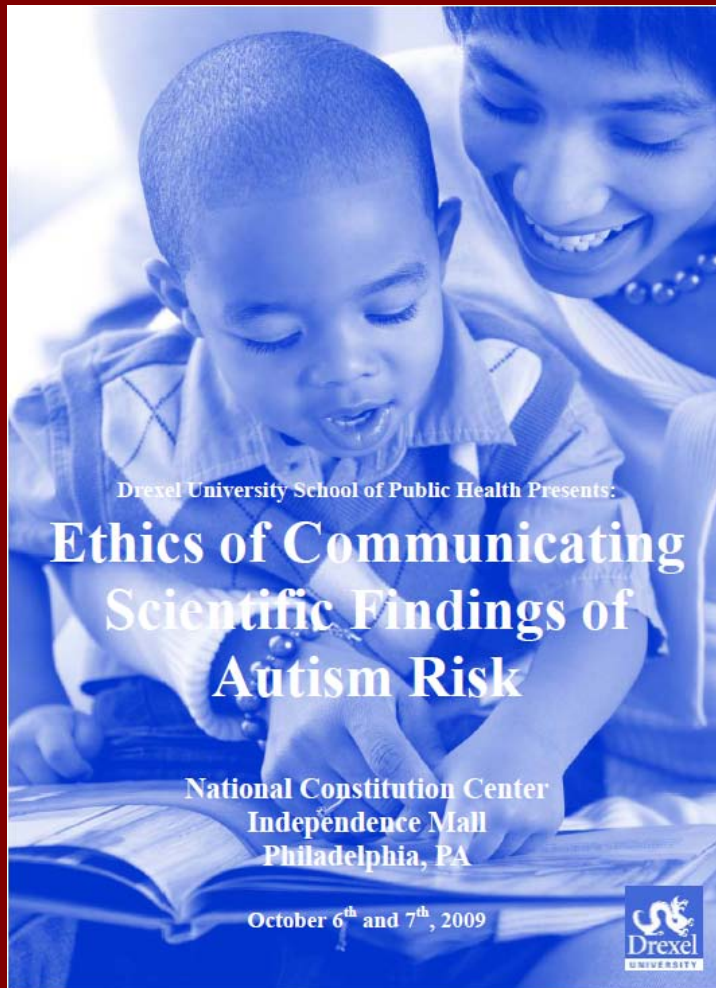
ing doctors, a failed  
 age and her own guilt,  
 McCarthy tells how son  
 recovered from autism

Hollywood Star of the Year



# How Can Risk Communication & Ethics Help us Address the Following?

- Culturally sensitive genetic counseling
- the communication of complex genetic test results and their uncertainty
- communicating potential harms from autism research to parents and patients
- The communication of complex etiologies to diverse stakeholders
- The Discussion of autism in an era of uncertainty and controversy



Drexel University School of Public Health Presents:

# Ethics of Communicating Scientific Findings of Autism Risk

National Constitution Center  
Independence Mall  
Philadelphia, PA

October 6<sup>th</sup> and 7<sup>th</sup>, 2009



Meeting funded  
by NIEHS,  
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Autism Speaks



# Goals of the Meeting

- Examine the ethical issues involved in ASD research and the dissemination of its findings;
- Bridge the gaps between ethics and research and communication practices by recommending specific guidelines or policy proposals;



# Goals of the Meeting

- Foster discussion between diverse stakeholders to facilitate the responsible dissemination of emerging knowledge to clinicians, genetic counselors, journalists parents, patients and others;
- Develop action areas for autism risk communication and ethics
  - Identify barriers and challenges
  - Propose Recommendations and next steps





## Autism in Adults

Diagnosis; Services;  
Long-term Quality of Life

## Recognition

Early detection

## Access to Services

Disparities; best-practice;  
cost-effectiveness

## Natural History

Behavioral; Biologic

# AUTISM RESEARCH

## Causes

Risk factors  
(genetic, environmental)

*Human studies*

## Treatment/ Intervention

Behavioral; Educational;  
Pharmacologic; Other



# Action Area #1

- The Role of Clinicians/Autism Service Providers in Disseminating/Translating Autism Research

## Action Area #2

- Balancing the Communication of Scientific Advances and Continuing Uncertainty- Strategies for Researchers and the Media

# Recommendations to Stakeholders

- Acknowledge that scientists and journalists have competing interests
- Work with PR office
- Don't over-interpret findings
- Clearly describe impact of findings
- Get scientists media training
- Special attention to online information
- The problem of inaction: if the wrong story is printed, correct it
- Dissemination of findings is grant-worthy

# Action Area #3

- **Considerations for Tailoring Risk Communication – Issues for Autism Risk Factors**

## Action Area #4

- Disseminating Results on Research Findings to Research Study Participants

# Next Steps

- This is a first step
- Foster community/stakeholder partnerships
  - For dissemination
  - For further research
- Foster more collaborations with academic risk communication scholars
- Archival history research
- Follow-up stakeholder meeting

# Next Steps

- IMFAR, AAHM, APHA
- Publish results of meeting consensus document
  - Academic journals
  - Popular media
  - Stakeholder publications



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